

The creation of the Tick-Borne Diseases Working Group was a milestone for Lyme patients and advocates. It finally gave them a seat at the table when Lyme disease was being discussed at the national level.

“Prior to this, the Lyme community was left in the dark without being considered,” said Jill Auerbach of Dutchess County, New York, one of 11 patients selected by the Department of Health and Human Services (HHS) for the six subcommittees of the Working Group. Now that the first phase of the group’s task is nearing completion, I wanted to find out how these patients felt about their experience.



I started with Lyme Disease Association President Pat Smith, a mother of two daughters

with Lyme. A prime mover and shaker, she has worked with members of Congress for more than 20 years to pass a bill that would include patients and/or family members, advocates, and treating physicians along with federal agency representatives. Smith was a key player when a group of advocates in December 2016 succeeded in having Lyme-friendly language included in the 21st Century Cures Act. HHS appointed her, along with Ben Beard of the Centers for Disease Control (CDC), as co-chair of the Disease Vectors, Surveillance, and Prevention Subcommittee, of which I also was a member. Smith made clear that for this interview, she spoke as an individual and not as a representative of the Working Group or HHS.

“The government has been making decisions affecting the lives of hundreds of thousands of people with Lyme disease and the public at large who were at risk,” Smith said. “They made decisions behind closed doors, without the voice of the most affected stakeholders, the patients.”

Smith said the legislation guaranteed that the federal advisory group would represent a diversity of viewpoints. This paved the way for including the perspective of the International

Lyme and Associated Diseases Society as well as that of the Infectious Diseases Society of America—and for transparency of the whole process. The Working Group is covered under the Federal Advisory Committee Act, which ensures that meetings are accessible and generally open to the public. Patient representatives can raise issues that are most important from a patient perspective and can fight to include those issues in any report, either as part of the majority opinion or as a minority report. This means patients’ voices will finally be heard, Smith said.

I asked several other patient representatives why they participated. Auerbach echoed my own sentiments about why she volunteered for a subcommittee. With a résumé boasting memberships in eight different Lyme and tick groups, including serving as co-chair of New York Senator Sue Serino’s Advisory Board on Lyme and Tick-Borne Diseases, Auerbach has been an outspoken proponent of focusing our efforts on ticks themselves. She said she believes it her duty to call for tick research to become a national priority. I also felt the call of duty to represent California. CDC maps make it look like Lyme doesn’t even occur in the Far West. I thought, if I don’t speak out, who will?



Monica White is president and co-founder of the Colorado Tick-Borne Disease Awareness Association and a former U.S. Forest Service wildlife biologist who has struggled with tick-borne diseases herself. She said she too felt compelled to use her voice to “help in this process of hope to represent those that are too sick to speak.” White, Auerbach, and I ended up together on the Disease Vectors, Surveillance, and Prevention Subcommittee, where, in spite of a high degree of consensus with non-patient members, we still ended up filing two minority reports.



David Roth, Lyme patient and lawyer recently retired from a multinational investment company, was appointed co-chair of the Testing and Diagnosis Subcommittee. He found that his background as the director of an advocacy group didn't really prepare him for discussing research at this level. Luckily, he was able to rely on another patient advocate on his subcommittee, Holly Ahern, associate professor of microbiology at SUNY Adirondack, who has a biology and research background. Roth said he leaned on her for the more technical topics. He wants more clinical trials to develop and validate new treatment protocols, especially new direct-testing technologies, and he's keen to "vastly increase the sums of money being put into research."

Roth noted: "Better diagnostics are the lynchpin for early, more effective treatment."



Holly Ahern has a daughter who was seriously ill with Lyme disease. Nominated by several state and federal legislators because of her leadership role on the Lyme Action Network and the New York State Senate Tick-Borne Disease Task Force Advisory Group, she was assigned to the Testing and Diagnosis Subcommittee. She felt that her knowledge of the scientific literature related to Lyme disease was particularly extensive. She says that the two patient/advocate members of the subcommittee held their own with the rest of the group, consisting of researchers and representatives from the NIH and FDA. This was an important point.

White believes that having more patients and advocates on the subcommittees would have

provided a better balance, though the work of the scientists and academics is critical to advancement of the science.

“The patient and advocate perspectives are very different from that of scientists or academics who have not been personally impacted by the devastating effects of many of these diseases,” White explained. “Priorities are often different from the patient perspective. You don’t ‘get it’ [understand the issues] the same way until you ‘get it’ [contract the illness].”

Subcommittees were deficient in patient members



Auerbach pointed out that several subcommittees were deficient in patient members, namely the Pathogenesis, Transmission, and Treatment Subcommittee, the Vaccine and Therapeutics Subcommittee, as well as the Other Tick-Borne Diseases and Co-Infections Subcommittee, which had one patient member each. It is hard for a single representative of a constituency to hold his or her own or to push agenda items alone. Particularly surprising were the unanimous votes on all issues reported out of the Vaccine and Therapeutics Subcommittee at the June 21 Working Group meeting, with no reference to the failed

LYMERix vaccine or the class action lawsuit. Unfortunately, Leigh Ann Soltysiak, the patient representative on that subcommittee, did not provide a comment, although I reached out to her multiple times. Pat Smith has submitted a minority report on the vaccine, which is still a controversial issue, so the discussion is not over; but still, the committees need better balance.

The Access to Care Services and Support to Patients Subcommittee had the most generous proportion of patient representatives of all the subcommittees. After some initial shuffling of membership, HHS installed Paula Jackson Jones as co-chair. She describes herself as a survivor of multiple misdiagnosed and mistreated tick-borne diseases who is now in full remission. She runs a successful Lyme advocacy organization in Maine, where she helps others connect to much-needed resources every day. She hoped that by taking that skill to a federal level she could make a difference for patients everywhere.

Process mandated by HHS



Jones alluded to the process mandated by HHS for conducting the business of the subcommittees. It was confusing to all of us at first, but as time went on and we were given more instruction and some leeway, it began to make more sense and fall into place. Several people complained about the tight timetable under which we were working. We rushed from deadline to deadline to prepare assignments before weekly telephone meetings for several months in the spring. Jones said forging a template is always difficult but thinks we made it

better for the next round. This phase will end with a report to Congress, which is due in December 2018. The next session will have two full years to complete the next report.

The fact that any member of the subcommittees (or the Working Group itself) can file minority reports gives patients a much more level playing field. All the patient representatives I spoke with felt their viewpoints were included in the final report, even if only as a minority report. Pat Smith and I added a strongly worded minority report relating to the CDC surveillance case definition being used for diagnosis (*see article elsewhere in this issue*). The academics, researchers, and government members on our subcommittee weren't willing to go as far as we wanted to on that subject, although they went further than I expected them to.

Auerbach expressed frustration that the draft of the Working Group's report to the secretary of HHS, which we reviewed at the June meeting, underrepresented the critical importance of tick research. Filing a minority report was not an option at that point, so she followed up with a letter to the Working Group urging them to provide more detail on rodent-targeted vaccines, tick population reduction strategies, personal protection, and landscape modification.

Although the current draft report includes some recommendations about tick-related research, Auerbach feels that it falls woefully short of what's needed.



Strictly speaking, Kristen Honey was not a patient representative when HHS appointed her as vice chair of the Working Group. She is, however, a late-stage Lyme disease survivor who has been on the patient side and, as she puts it, “fell between the cracks of a broken medical system.”

“Overcoming Lyme disease with coinfections was the most difficult challenge—by far—that I’ve ever faced in my life,” Honey said.

Most patient members reported a positive experience

Most patient members reported a positive experience with the subcommittees overall. Pat Smith is happy that Lyme patients/advocates are finally afforded the same rights patients with other diseases have—“a voice in advising how the government should be responding to their tick-borne disease.” Holly Ahern rejoiced that “it is the first time in the 40-year history of Lyme disease in the U.S. that persons affected by TBDs were included in the making of policy about the diagnosis and treatment of their disease.” She is, however, reserving further comment on the importance and effectiveness of the Working Group until the final report is released in December.



I'll give the last word to Wendy Adams, a patient and advocate with the Bay Area Lyme Foundation and co-chair of the Pathogenesis, Transmission, and Treatment Subcommittee (though she speaks for herself and not for the Working Group). She thinks that the Working Group has provided a chance to bring both data and patient experience to the government and say, "How can we change this?"

"Part of the most important job we have is bringing light to the dark corners—the truth about how many cases are misdiagnosed early in infection, when treatment has the best chance of success, how many people don't recover fully and the degree to which patients'

lives are affected by these diseases,” she said. “Recounting the whole story in one place for Congress to understand is crucial to educating them on the scale of the problem and to defining the overwhelming gaps in our knowledge of how to best prevent, diagnose, and treat these diseases.”

Editor’s note: Any medical information included is based on a personal experience. For questions or concerns regarding health, please consult a doctor or medical professional.